Strengths Classification of Social Relationships Among Cybermothers Raising Children with Autism Spectrum Disorders

Laura Dreuth Zeman, Jayme Swanke, and Judy Doktor

Abstract

Children with Autism Spectrum Disorders (ASD) and their families are different. Parents often surf the Internet in search of supportive solutions to the unique challenges they face. One source of insight for parents raising children with ASD comes from blog writers and the parents who surf the net to read their blogs, or cyberparents. The study here intends to add insight into how cybermothers raising children with ASD experience their social networks. Such perceptions may potentially help educators foster positive partnerships with similar parents. The researchers undertook this phenomenological study with the assumption that cybermothers who blog expressed their authentic voices and would best represent their lived experiences. Eighteen months of data collected from 24 blogs was coded within a strengths framework that classified relationships into inhibiting and assisting categories and sorted it by themes that emerged within each strength category. Inhibiting relationship themes included role strain and isolation. Assisting themes were examined within the context of supportive relationships.

Key Words: mothers, autism spectrum disorders, ASD, strengths, social, relationships, networks, networking, blogging, online, supports, cyberparents, parents, families, blogs, Internet, roles, isolation, special needs, education, children with disabilities, disability, teachers

Introduction

Raising a child with Autism Spectrum Disorder (ASD) can have a tremendous impact on parents. The purpose of the present study is to develop an understanding of how cybermothers who blog, a group of mothers who blogged about their experiences raising children with ASD, perceived their social networks. This insight could explain, in part, their influence in shaping practices and meanings among other parents who surf the Internet seeking alternative information about children with ASD. Further, we assumed that such an understanding would be useful to educators who work with similar families because it might provide insight that could help foster supportive home—school partnerships.

Parenting children with ASD requires adapting to a variety of challenging behaviors and communication patterns. Children with ASD typically display the following characteristics: impaired social interaction, impaired communication, repetitive or stereotyped behavior, abnormal sensory perception, and impaired cognition (Clarke & van Amerom, 2007). Typically, three recognized diagnoses constitute ASD: Autism, Asperger Syndrome, and Pervasive Developmental Disorder-Not Otherwise Specified (CDC, 2006). Generally, children with Asperger Syndrome have a much higher level of intellectual functioning than those in the other two categories, but their social skills are not commensurate with their academic abilities and their chronological age.

Perhaps the increase in the diagnosis of ASDs over the last decade can explain in part the increase in public attention to these disorders. ASDs are now ranked second, behind intellectual disabilities, as the most common childhood developmental disorders (CDC, 2006). In 2006, the Centers for Disease Control (CDC) estimated that 1 in 150 (0.6%) children, or 46.5 million youth between birth and college, in the United States have an ASD (CDC, 2006). It logically follows that this increase in incidents accompanies an increase in the cost of care. The potential educational costs associated with educating children with ASDs are estimated at roughly \$15,000 a year while additional therapies may cost families on average \$22,000 annually thus bringing the potential cost of care to an estimated \$660,000 over the first 18 years (Chasson, Harris, & Neely, 2007). It is plausible that families, school districts, and universities in the United States combined may annually pay around \$1.7 trillion to care for youth with ASD.

Cyberparents

Children with ASD and their families are often misunderstood (Cole, 2007). Therefore, it is likely that mothers may seek support or information

from sources that mirror their own interpretations of their experiences. With access to the Internet, it is likely that parents seeking supportive solutions to these unique challenges may reach out to members of virtual networks. This phenomenon is possible as more families have in-home access to the Internet. Currently, it is estimated that as many as 80% of U.S. families have access to the Internet from their homes, while approximately 90% of public libraries in the U.S. provide free Internet access (American Public Library Association, 2009). While in-home Internet access is becoming customary, it is important to note that Caucasian professionals are most likely to have Internet access at home, leaving low-income, minority, young, single-parent-headed households among the families most likely living in homes without Internet access (Madge & O'Connor, 2006).

The research on the use of virtual social networking among parents is emerging. Clare Madge and Henrietta O'Connor (2006) studied blogs of new parents. They found that cyberparents used the Internet to form social networks, build coping skills, and access usable information that supplemented professional and commercial resources. They suggested that virtual communities play an important role for some parents in shaping their practices and meanings. The authors caution that a form of segregation is emerging, called cyberexclusion, as parents who lack access to the Internet are excluded from alternative information and the social networks that shape meaning.

Research on the use of the Internet among parents raising children diagnosed with ASD is also emerging. For instance, Jaci Huws and her colleagues (2001) found that parents of children with ASD seek virtual support to help adjust to complicated roles and to supplement medical information. Amos Fleischmann (2004) studied online parent narratives to understand how cyberparents communicated their adjustment to their children's ASD diagnoses. He found that cyberparents typically discuss shifts in roles from parenting to care managing following the initial diagnosis and tend to present themselves as advocates rather than victims. He also found that cyberparents used the Internet for social networking with other parents of children with ASD and to share information. Studies of cyberparents are important because they can help explain how parents use their relationships with schools and others to foster resilience.

Strengths Framework

The strengths framework seeks to understand people within their relationships and seeks to understand how social relationships facilitate resilience (Rapp & Goscha, 2006). Therefore, it is an excellent framework for understanding social relationships such as those examined within the context of this article. Fostering resilience, or understanding how people cope and thrive, is a

central goal of strengths approaches. This framework assumes that people experience both inhibiting and assisting relationships. Inhibiting relationships restrict access to opportunities and resources. For example, people in inhibiting relationships may appear stigmatized and isolated. As a result, they may lack confidence or experience reoccurring conflict and rejection. For instance, mothers of children with ASD who perceive educators as condescending might avoid outside help and encourage others to reject care opportunities. In contrast, assisting relationships tend to validate and encourage relationships outside the social network. Therefore, mothers of children with ASD who perceive relationships with educators as assisting may be more likely to inspire other parents to engage in constructive home—school partnerships.

Prior studies that applied the strengths framework to parents primarily examined cultural, ethnic, or socioeconomic networks (Hill & Bush, 2001; Sy & Schulenberg, 2005). For instance, Laurence Steinberg and his colleagues (1991) examined parenting style across ethnic and socioeconomic groups. Similar to prior studies that sought to understand how parents draw support from cultural networks, the study here intends to add insight into how cybermothers who blog while raising children with ASD experience their social networks. Such perceptions may potentially affect the broader discourse about facilitating resilience among parents raising children with ASD.

Purpose of the Study

This qualitative study was designed with the goal of gaining insight into how cybermothers who raise children with ASD experience their social relationships. From the perspective of a parent, what aspects of their social relationships are inhibiting, and what relationships do they perceive as assisting? The findings describe how these parents present their relationships in public blogs, which can potentially influence how other parents who surf the Internet seeking alternative sources of support may interpret their own relationships. Information created from the parents' point of view will help educators relate to similar parents and may help them form parent—school partnerships that foster resilience.

Method

Sample

The process of identifying and selecting blogs for inclusion in the data set was purposeful and rested on the phenomenological goal of capturing, as comprehensively as possible, the authentic voice of the set of parents who intentionally share their experiences on public blogs. The study met criteria for human subjects research involving existing data. Internet searches for blogs written by parents raising children with ASD were conducted. After identifying the initial set of blogs, we applied a criteria for selection in the study. First, the blogs had to contain eighteen months of existing data, with a minimum of one entry per month. We used eighteen months of data to capture expressions of ongoing struggles and successes, providing deep meaning to the mothers' stories. We wanted to capture experiences that overlapped school years to assure that meanings were independent of specific teacher—parent relationships. Second, we limited the blogs to those written by authors who focused on their own personal experience to focus the analysis on their world from their own point of view. Although there were two blogs authored by cyberfathers, they were excluded to keep the sample homogeneous. In the end, 24 out of the 100 public blogs authored by cybermothers raising children with ASD fit the full criteria for inclusion in the sample.

Data

The analysis file was created by selecting the reflective statements that examined personal experiences that related to parenting children with ASD. Data strings consisted of statements that explained the experience within the context of relationships. Thomas Groenewald (2004) referred to this as "delineating units of meaning" (p. 17). That process also involved eliminating statements classified as intellectual property, political or social commentary, news articles, advertisements for events on autism, updates on the child without reflection, pictures or graphics, and updates about other members of the family unrelated to the theme of the study.

Data Analysis

Content analysis coded data strings into strengths categories to deepen the understanding of the lived experiences of this group of parents. The analysis used the strengths framework as a template to sort the data into categories of inhibiting and assisting relationships. The data strings were further clustered into units of meaning to form themes within each strengths category. These emerging themes were role strain and isolation within the category of inhibiting social relationships. Each theme reflected characteristics of relationships that influence the perception of the relationship as inhibiting, according to Rapp and Gosha (2006). The data statements within assisting social relationships were grouped according to the type of relationship, that is, family or friends. These groupings reflected the discourse presented in the blogs, and the research team attempted to remain consistent with the general meaning of the bloggers' portrayal of their social networks.

Code verification consisted of assuring agreement among three researchers. This process reduced the bias that influences data interpretation (Denzin & Lincoln, 2005). This verification process involved comparing the results of independent analysis and reconciling any differences in interpretation. In the case of different interpretations, either the researchers negotiated a common interpretation, or they agreed to remove the statement from the findings. Therefore, the final classifications represent the three-researcher agreement on themes, coding, and interpretation.

As with all qualitative analysis, the experiences of the research team influence data interpretation. The research team consisted of two university faculty members and a graduate assistant. One faculty member is a professor of social work and women studies with a clinical background in family therapy and mental illness. The other faculty member teaches in teacher education, has a background in special education advocacy, and had prior experience administering school and district special education programs. The graduate assistant studied psychiatric and addiction rehabilitation. They worked together to shape this understanding of the data while attempting to present the mothers' voices locked in their unique context.

Themes were included in the findings if they appeared in at least 6 different blogs, or at least 25% of the blogs in the sample. This threshold was set to assure that the findings emphasized salient themes across the blogs. This process is referred to as "extracting general themes" rather than reporting unique experiences (Groenewald, 2004, p. 17).

Three common themes labeled role-strain, isolation, and supporters emerged. The definition of role strain applied in analysis was adapted from family theorist Hamilton McCubbin (1983) who identified attributes of role strain as making decisions alone, disciplining children, combining mother and father roles, handling family finances, and engaging in legal or educational advocacy. The definition of isolation is based on the work of researcher Brian Boyd (2002) who found that parents of children with autism experience high levels of stress when they respond to a lack of support from others by withdrawing. Therefore, isolation was identified when bloggers discussed withdrawing due to their perceptions of lack of support. Supportive relationships existed with partners, extended families, friends, and members of formal and informal social groups, similar to Boyd's prior findings. We extended Boyd's work to include three new categories of assisting social relationships. These are the relationship between the mother and her child with ASD, her relationship with her child with typical development, and the virtual relationships she formed with other cybermothers who blog and with her readership.

Verbatim quotes were used to demonstrate major findings. However, in some cases, comments that were sexually explicit, offensive, or used hate speech were replaced with brackets [...] to comply with writing style guidelines.

Findings

The 24 blogs represented the writing of cybermothers who were between the ages of 32 and 45. Primarily, they were raising children diagnosed with Asperger Syndrome and Pervasive Developmental Disorders. Three of the children had been diagnosed with Autism. Their children were primarily in prekindergarten or grade school and between the ages of 5 and 9 years old. During the study period, half of the mothers were employed, either working professionally outside or inside the home. On average, their children attended between four and five therapy programs in addition to supplemental school-based services. While specific variables on race, education, and social class were not coded, based on the review of the information presented on the blogs including photographs and personal histories, it is assumed that these bloggers mirrored the cyberparents discussed by Madge and O'Connor (2006) to the extent that they appeared to be primarily Caucasian, college educated, and middle class.

Much of the discourse regarding professionals focused on home–school relationships. Parents also formed secondary professional relationships with behavioral therapists or extracurricular instructors. Throughout the data, parents identified significant relationships with their children, partners, friends, extended families, and fellow bloggers. Relationships with educators were classified as both inhibiting and assisting. Inhibiting relationships with educators existed within the context of disputes over levels of educational support, concerns about the educators' understanding of ASD, and negative interactions between the educator and the parent or child. Within supportive relationships with educators, parents reported that educators worked to help the child feel comfortable and to help the mother by incorporating her understanding of her child's needs into the learning environment.

Inhibiting Social Relationships

Often, the themes of role strain and isolation emerged as these women expressed circumstances that they perceived as out of their control. Typically, these were within the context of home–school relationships.

Role Strain

Role strain emerged in the data when cybermothers who blog were combining parenting with additional roles, such as therapist or advocate. This role

strain resulted as mothers functioned as case managers to balance expanded advocacy roles managing legal, educational, health, and insurance concerns affecting their child's care. One cybermother wrote, "I'm feeling so overwhelmed because I have so much to do, and I just don't know how I am going to get it all done in time. It sure would be nice if I had some help!"

Role strain themes often emerged within the context of home–school relationships. Many mothers portrayed themselves as frustrated advocates who fought for services that were not available in the district. This gap appeared to feed role strain as mothers voiced feeling "compelled" to monitor the schools their children attended. One mother expressed frustration and advocacy when she wrote that she needed to monitor the school to assure that, "we are [not] veering off into different philosophical perspectives, I am ready to intervene at the appropriate time to make sure that we don't continue down these divergent paths." That mother feared that if the school changed its intervention, such an alteration might thwart her child's growth.

Another mother demonstrated the role strain theme according to specified roles. She wrote, "I'm ok. Really. Just very [...] busy. I need a personal [...] assistant. And a secretary. And a butler. And a maid. And a nanny. And a chauffer. And a maybe a clone or two." She questioned whether she "could get through the rest of her life fighting to keep up" with her child's changing symptoms and corresponding changing educational needs. She appeared to pressure herself to achieve results to improve her child's condition rather than conduct realistic self-appraisals or forge effective partnerships with educators.

Isolation

Mothers portrayed themselves as not only lonely, but as isolated from others who might understand their experience. One mother identified her isolation by simply stating, "I'm basically a hermit. I keep to myself." Another mother expressed this theme when she wrote, "I am without support and the closeness that I need so much." Though many of the working mothers interacted with others through their jobs, their complex responsibilities coupled with work appeared to take time away from engaging in meaningful friendships.

One blog entry reflected how these cybermothers connected with isolation the unique needs attributed to raising a child with ASD. She wrote,

I have little to no support up here because the friends that I do have do not help me watch [CHILD] on a regular basis, only in emergency situations. Therefore, I am without support and the closeness that I need so much. I am sure that I will adjust with time and learn to be alone again like I have been for so many years. The friends that I do have don't have children so we don't get together to do play dates. I have searched for

groups of moms who have children [CHILD]'s age and are autistic but have had no luck because there are no groups that have been formed.

In this context, the mother made unsuccessful attempts to connect informally with other mothers and reflected on her longing for a formal peer support group organized for parents raising children with ASD.

Assisting Social Relationships

The theme of support emerged in the context of mothers' relationships with their children, both the children with ASD and their other children considered typically developing. Supporters also included partners, extended family, friends, other parents with similar experiences of raising children diagnosed with ASD, and educators. Interestingly, the social world they created through blogging emerged as an additional support theme in the analysis.

Child with Autism

These cybermothers who blog often fondly reflected on interactions with their children. One mother's reflection mirrored the theme. In this passage, she reflected that she missed her son after spending a day shopping without him. "That's when I made the realization....A turbulent, challenge-filled day with [CHILD] is infinitely better than a placid, uneventful day without him."

Children with Typical Development

The data reflected similar themes of support received from children with typical development who mothers wrote about as a source of comfort and support. One mother's reflection on the nature of her relationship with her children at a play lot in a local park reflected this theme. She wrote,

So we were out enjoying the sunshine and perfect-temperature fall day, and I was swinging [OTHER CHILD] in the toddler swings... It was so simple, and taught me so much, of simply being.

Partners

Cybermothers who blog described how their partners responded to problems or provided nurturance and intimacy. One mother whose child struggled as he adjusted to a transitional kindergarten program reflected on how she managed to balance her role strain while confronting educators as an advocate for her child. She said of her anger and frustration, "My support system gets most of it, while my husband, my rock, gets the most of anyone. The highest highs and pretty low lows."

Extended Family

Throughout the blogs, the theme of extended family as supporters emerged, especially in the context of emotional support or holiday celebrations. One

cybermother wrote, "what's most important at this point in time is that we are close to our family and have the support that is so desperately needed." Some parents received regular support through visits or phone calls. Another mother expressed the comfort she attributed to her parents respect for her choices when she wrote.

And can I just give a shout-out here to my parents, who have never given me [...] about my parenting, who have always trusted that I will make the best decisions I know how, who have faith in me and in [SPOUSE]? It feels so comforting to be so supported.

Friends

Friends are features of enabling niches when they embrace persons where they are and do not treat them as outcasts or stigmatize them (Rapp & Goscha, 2006). This theme of friends as validators, sounding boards, and as observers with constructive support emerged in the analysis.

One mother's reflection highlighted the importance these mothers placed on friendship. She wrote,

They were right there beside me when [CHILD] was diagnosed. They stood beside me as I fell into my hole so deep, and with their presence and their loving words, helped me as I pulled myself back out of it. They love [CHILD] dearly because they have known him his whole life, and I love their kids just as much...I am so glad, so grateful, that we ended up navigating through this motherhood journey together.

Parents of Children Diagnosed with Autism Spectrum Disorders

Another support theme that emerged in the analysis was the theme of receiving support from other parents of children diagnosed with ASD. In this data set, these relationships served complex needs of affirmation, advocacy, and education. One mother wrote, "Each one of us hold golden nuggets that somehow benefit the next one." By identifying the network as "exclusive but growing sisterhood any of us would love not to be a part of" this mother underscored the shared experience that she labeled as "helplessness and frustration" that, while often unspoken, binds these cybermothers who blog.

Educators

Relationships with educators were classified as supportive when parents understood their choices to be aimed at accommodating their child's unique needs. This often meant helping the child feel special, creating unique learning opportunities, pointing out their child's successes, intervening in potentially unsettling peer interactions, and, in many cases, remediating tantrums. In many cases, the positive relationships with educators extended to the building

and service personnel. One of the cybermothers described her understanding of a bus driver as a person who is "so sweet…she reports he is always talking to her as she is driving along." This relationship created an environment where the child felt comfortable and allowed the bus driver to understand the child.

Blogging

The theme of blogging as a source of social support emerged during the analysis as many of the mothers discussed the role blogging played in their daily lives. In the following case, the author thanked her readers for their support:

I'm humbled and overwhelmed by the outpouring of support and the depth of understanding that followed my last post. Thank you all. I'm sorry that you understand so well; but I really am thankful that we've all found each other.

The blogs also offered the authors a space to vent without having to face the direct personal reactions of family, friends, or educators. At times, the mothers thanked people who responded to their blog for their comments and support. One mother called her narratives "blog-o-therapy" and conceptualized her blog as a therapeutic space where she organized her thoughts, expressed herself, and "just breathed."

Discussion

The themes from this analysis indicate that these cybermothers who blog demonstrated complex social worlds that included interpersonal relationships, emotional experiences, and virtual interactions. First, these complex women present images of both strength and vulnerability. They had support, and yet at times they felt isolation and despair. These themes create a picture of cybermothers who may create uniquely blended social worlds to satisfy their need to connect with others for acceptance and encouragement. In part, they reached out to parents in similar situations to resolve perceptions of despair and isolation. As a result, they could reposition their use of supporters to cope with stresses as new challenges emerged or as the structure of their social worlds shifted. At times, they relied on their "blog-o-therapy" to vent, share intimate details, and to make sense of their lives. They also drew affirmation and insight from fellow bloggers and their own readers who served to normalize their physical and emotional realities.

These themes also represented conflicting emotional aspects of the social lives of these cybermothers who blog. All mothers discussed their love for their child, family, and friends along with frustrations and experiences of isolation. For instance, themes of role strain often emerged in the context of mothers

who perceived they were challenging people who they perceived as resisting their efforts to help their children. Role strain occurred as they took responsibility for coordinating their child's educational and therapeutic interventions. They often expressed a shared belief that they were the only people who understood the totality of their child's needs. Consequently, they did not trust the coordination and scheduling of these activities to anyone else. This multifaceted expectation that coupled desires for improvement and lack of trust in others explains their role as parent case managers (i.e., mothers who believe their role is to supervise their child's remediation).

These findings build on the understanding of blogging cyberparents raising children with ASD and their social networks developed by prior scholars (Clarke & van Amerom, 2007; Fleischmann, 2004; Huws et al., 2001). The other researchers found that parents used Internet sites to seek information about ASD and treatment as well as to locate advocacy information. The analysis here indicated that cybermothers fostered ongoing supportive relationships with other cybermothers and with their own readership. These findings also build on Boyd's (2002) understanding of support persons that influence the lives of parents raising children with ASD by identifying additional supportive relationships. Specifically, these cybermothers considered their relationship with their children as sources of social support.

Recommendations for Educators

These insights about cybermothers can provide stimulus for educators to use a strengths perspective to understand parents raising children with ASD. Educators may benefit by understanding these parents as complex individuals who can provide insight and may need support. Professionals may view parents as capable of directing care and being the primary voice in determining service plans. Some parent—school partnerships could be enhanced if educators incorporate parents' needs, such as respite care, into school services or connect parents to community resources. Educators may also find that empowering parents through parent-centered planning from a strength model of ability may meet parents' expectations.

Communities can examine local capacity to meet the educational challenges for children with ASD. The mothers in this study expected high levels of local school capacity and freely praised teachers and school districts that met these expectations. Obviously, a parent with the individual capacity to understand specialized programs and due process rights has an advantage over parents who do not possess this capacity. Some would argue that this advantage is inherently unfair, as parents with limited resources generally have less time to devote to garnering this individual capacity. This study found that

cybermothers who blog help build the capacity of other parents by educating them about advocacy and resources. Schools can advance their capacity by incorporating flexibility into their special education resources to accommodate a range of interventions requested by parents.

Local communities can also build capacity to support parents raising children with ASD by creating virtual networks for parents within their school districts. These networks could be useful to facilitate successful advocacy and improve home—school relations. It is possible that parent resource centers can incorporate virtual networks. Likewise, parent centers located within school settings could incorporate peer support into their models. These peer support networks could help parents identify problems, find referral sources, and evaluate interventions.

Limitations

The main study limitation is grounded in the origins of the data. First, we rested the accuracy of our analysis on the assumption that the cybermothers who blog represented their authentic voice and that the data strings were a personally constructed windows into the authors' worlds. Also, these blogs represent the expression of a subgroup of parents with access and proficiency in technology sufficient to establish and maintain public blogs. We further acknowledge that these blogs did not exist in isolation. Rather, over the one and a half year period we examined blogs, we observed the formation of an informal ring of communication. In fact, there were several instances where specific comments included in the study were referenced across this informal virtual network.

Finally, as this study only examined the writings of mothers of children diagnosed with Autism Spectrum Disorders, it is not possible for the researchers to generalize to other parents. Therefore, while these findings are specific to this set of mothers, it is not clear that these findings are unique to this group. Future studies could enhance the understanding of cyberworld expressions of parents raising children with a variety of disabilities and special learning needs.

Conclusion

Although parents raising children with ASD are different and may sometimes be misunderstood, this study found a group of these parents to be dynamic and complex with deep commitments to their children and with high levels of frustration related to advocating and isolation. The parents in this study shared passionate feelings toward their children and their supporters, partners, friends, family, educators, and fellow bloggers. They expressed great

appreciation for educators who sought to understand their children within the context of their families and within their unique experience of their ASD symptoms. In the cyberworld these mothers created, they saw themselves and each other as experts on ASD and as vital resources for persons seeking information on ways to foster success for their children.

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